

WHAT IS KABUKI SYNDROME?

Kabuki Syndrome is a rare genetic disorder, estimated to affect ~1 in 10,000 births. Kabuki Syndrome can lead to a broad range of possible adverse health effects, including intellectual disability, immune deficiencies, cardiac and kidney abnormalities, and growth deficiencies, to name a few. It is caused by two known gene mutations, however it is believed that there are possibly other genes yet to be identified. These disruptions in gene expression can lead to a myriad of health related problems, some of which can be debilitating and require lifelong therapeutic interventions. There is no cure for Kabuki Syndrome. But, there is *hope*.

WE ARE LEADING THE WAY

The **Kabuki Syndrome Foundation** is the only organization dedicated to accelerating research efforts that show promise to treat, prevent or cure Kabuki Syndrome. The Foundation is led by a powerhouse board of directors who are all business leaders in their fields and parents or family members of a child with Kabuki Syndrome.

We have built a coalition with major research centers globally, including Johns Hopkins / Kennedy Krieger and Boston Children's Hospital, and are influencing the direction of future research efforts. Funds raised are being directed toward key Centers of Excellence, targeted research programs, and several enabling efforts that support the creation of a collaborative research network, such as patient registries, bio-repositories and clinical trial readiness.

OUR IMPACT

Programs highlighting our impact:

- Secured \$3MM in funding to support operating costs for the Roya Kabuki Program at Boston Children's Hospital for 5 years; with \$500K in the pipeline
- Partnering with data science company AllStripes; a powerful platform that accelerates research and possibly drug development
- Facilitating cross-institutional collaboration meetings between Centers of Excellence to standardize data for clinical research
- Consulting with a biotech company on clinical trial readiness

THE OPPORTUNITY IS NOW

Many Kabuki Syndrome research projects are reaching critical junctures in their progress, showing promising results in preclinical studies. Coupled with the recent progress in epigenetics research, there is consensus that within the next three to five years a drug therapy targeting the Kabuki Syndrome gene mutation or the resulting effects of it could be available.

A breakthrough of this magnitude would not only impact the individuals affected by Kabuki Syndrome but would also have wide-ranging implications on the treatment of any number of other rare diseases, including those with neurological deficits.

With your support, we can accelerate research that will produce life changing treatments

ANNUAL RESEARCH CONFERENCE

The Kabuki Syndrome Foundation's Annual Research Conference supports several of our initiatives by facilitating information sharing and collaboration across the KS community of families, scientists, clinicians and industry partners. It also kicks off our annual fundraising campaign.

This year's conference will be held "virtually" on **October 22-23**, 2021 with hundreds of expected participants across the Kabuki Syndrome scientific and patient communities.

Event details and registration can be found on our website: KabukiSyndromeFoundation.org



2021 Annual Campaign & Research Conference

SPONSORSHIP OPPORTUNITIES

SUPPORT KABUKI SYNDROME FOUNDATION

We invite you to become a conference sponsor and contribute to our annual campaign. *Every gift matters.* Accelerating the discovery of therapeutic treatments for Kabuki Syndrome is at the heart of our mission. Your generous gift will help drive advances in new areas of research, support the creation of a collaborative research network, and provide important educational materials to the Kabuki Syndrome community to support research recruitment efforts. Founded in 2017, the Kabuki Syndrome Foundation is a 501(c)(3) non-profit corporation.

SPONSORSHIP LEVELS AND BENEFITS

PLATINUM \$10,000+

- Featured on conference webpage and Facebook groups
- Special recognition during the virtual conference via audience chatroom 4 x throughout the livestream event
- Special recognition at the start of the conference, to include branded logo and company mission statement
- Named sponsor of one of the research presentations
- Corporate Logo will be displayed from 10/22/21 to 12/31/21 on KSF website in 2 prime locations
- We will post one custom Company Story on Social Media (includes 2 Facebooks groups with a combined 800+ members)
- Special recognition included in post conference email correspondence to all registered participants, including logo and website address.

PRESIDENTIAL \$5,000

- Featured on conference webpage and Facebook groups
- Special recognition during the virtual conference via chatroom 2 x throughout the livestream event
- Special recognition at the start of the conference, to include branded logo and company mission statement
- Sponsor of one of the research presentations
- Corporate Logo will be displayed through 10/01/21 to 12/31/21 on KSF website in 1 prime location

VISIONARY \$2,500

- Featured on conference webpage and Facebook groups
- Special recognition during the virtual conference via chatroom 2 x throughout the event
- When transitioning between breaks and presentations, sponsor will be recognized via branded logo slide when transitioning between presentations and breaks.

PREMIER \$1000

- Featured on conference webpage and Facebook group
- Special recognition during the livestream conference
- When transitioning between breaks and presentations, sponsor will be recognized via branded logo slide when transitioning between presentations and breaks

SUPPORTING \$500

- Featured on conference webpage and Facebook group
- Special recognition during the livestream virtual conference

ENDURING \$250

- Featured on conference webpage and Facebook group
- Special recognition during the livestream virtual conference

2021 SPONSOR PAYMENT DETAILS & DEADLINE

Guaranteed Corporate Sponsor Media Shoutout deadline: **October 10, 2021**

Please make checks payable to: **Kabuki Syndrome Foundation, PO Box 214, Northbrook, IL 60065**

Payments via credit card can be made by clicking [HERE](#)

For wire instructions, please reach out to info@kabukisyndrome.foundation.org